

Advocating for High Quality Healthcare

Speakers:

Dana Sciullo, MOT, OTR/L

Charlotte Woodward

Brian Chicoine, MD

March 11, 2026



*NDSS is creating a world where individuals with
Down syndrome thrive.*

NDSS Core Pillars

NDSS supports and advocates for the Down syndrome community by focusing on four key pillars:



**Resources
& Support**



Research



**Advocacy
& Policy**



**Community
Engagement**

NDSS Events



[NDSS Gala & Auction](#)
March 12, 2026
New York City, NY



[Brighter Futures Conference](#)
March 27 - 28, 2026
Worcester, MA



[Racing For 3.21](#)
March 21, 2026
Virtual



[Down Syndrome Advocacy Conference](#)
May 11-13, 2026
Washington D.C.



[Run For 3.21](#)
March 21, 2026
West Coast



[New York City Buddy Walk](#)
September 12, 2026
New York City, NY



Advocating for High Quality Healthcare

Agenda

- Introduction by Dana Sciullo at 12:00pm EST
- Charlotte Woodward (self advocate)
 - Personal experiences advocating for healthcare
- Dr. Brian Chicoine
 - Tools and guidance to partner effectively with clinicians
- Q&A
- Closing at 1:00pm EST

Charlotte Woodward



- Programs Associate at NDSS
- Supports the development of programs including education, employment, policy and advocacy, and health and wellness
- Graduated Summa Cum Laude from George Mason University with a bachelor's degree in sociology with a concentration in inequality and social change
- Charlotte Woodward Organ Transplant Discrimination Prevention Act

Self Advocacy in Healthcare

Here are a few ways medical professionals can make me feel more comfortable:

- Greet me and speak to me respectfully
- Presume competence
- Show interest in me and my life
- See me as a person rather than as a diagnosis
- Ask for permission before touching me
- Speak directly to me
- Thoroughly explain all procedures
- Ask me if I have questions

Clinician Education

Self-Advocacy at Medical Appointments

Why I'm going:

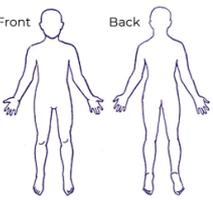
- Healthy check-up _____
- Sick: _____
- Injured: _____
- Other: _____

When my symptoms started: _____

My symptoms:

Where my symptoms are:

Front Back



How you can help me feel comfortable:

- Tell me what you're going to do.
- Talk slowly.
- Write information down.
- Use hand gestures.
- Use pictures.
- Avoid medical jargon.
- Talk to me first, not my support person.
- Bright lights bother me.
- Loud noises bother me.
- Other: _____
- Other: _____

My questions & concerns:

Wong-Baker FACES® Pain Rating Scale



0 No Pain 2 A Little Pain 4 A Little More Pain 6 Even More Pain 8 A Whole Lot Of Pain 10 Worst Pain

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PRACTICING INCLUSIVE MENTAL HEALTHCARE
of Individuals with Down Syndrome



CARE DOWN SYNDROME



national down syndrome society



Primary Care Provider's Guide to WOMEN'S HEALTH AND DOWN SYNDROME



national down syndrome society
ndss.

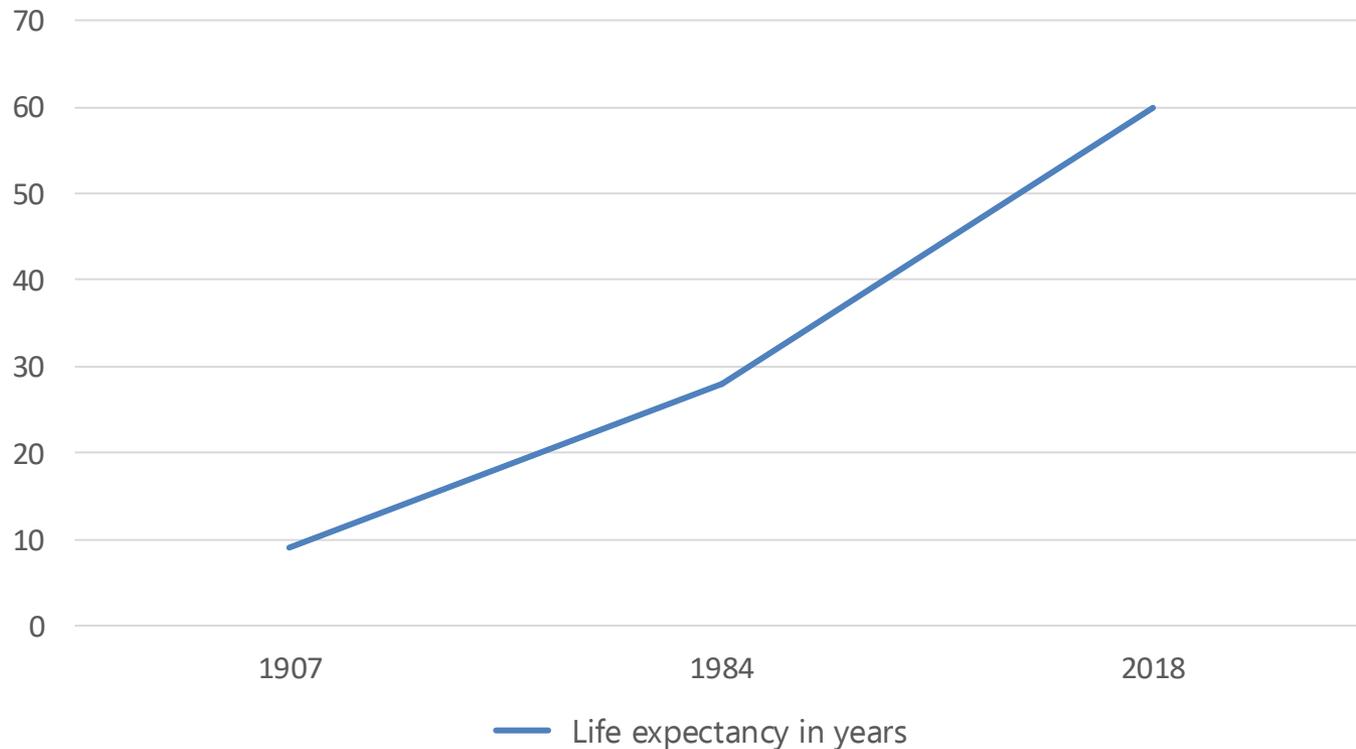
Brian Chicoine, MD

- Medical Director Advocate Medical Group Adult Down Syndrome Center
- Faculty, Advocate Lutheran General Family Medicine Residency
- NDSS Scientific and Clinical Advisory Board Member
- CARE Down Syndrome Lead Author and Reviewer



A Growing Need

Life expectancy in years



Bittles, 2004, Coppus, 2008, Glasson, 2002, Zhu, 2013

8-Fold Increase in Adult Population

People with Down syndrome in the United States

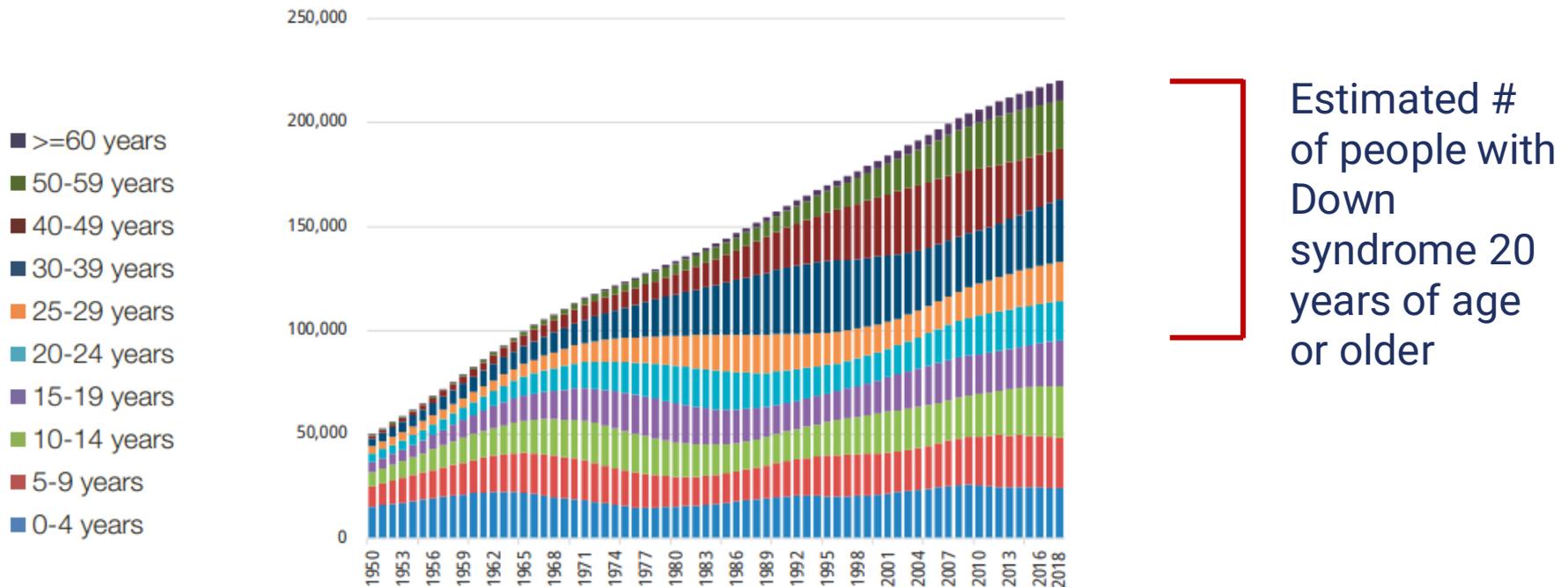


Figure 5. Population of people with Down syndrome in the USA, 1950-2018

Who is Providing Medical Care?

- 5% of adults
 - Down syndrome specialty clinics
- 95% of adults
 - Family physicians
 - Internists
 - Geriatricians
 - Other primary care clinicians

What Can You Do?

Strategies

- Identify clinicians
- Increase awareness in medical settings
- Provide critical medical and functional information to providers and people with Down syndrome
- Share resources

H My Health Passport H

! If you are a *health care professional* who will be helping me, **PLEASE READ THIS** **!**
before you try to help me with my care or treatment.

My full name is: _____
I like to be called: _____
Date of birth: ____ / ____ / ____
My primary care physician: _____
Physician's phone number: _____

Attach your picture here!

This passport has important information so you can better support me when I visit/stay in your hospital or clinic.
Please keep this with my other notes, and where it may be easily referenced.

My signature: _____ Date completed: ____ / ____ / ____

Relationship: _____

preferred language, sign language, I sounds, also state if extra time/

CARE Down Syndrome

A Clinical Education Hub for Healthcare Professionals

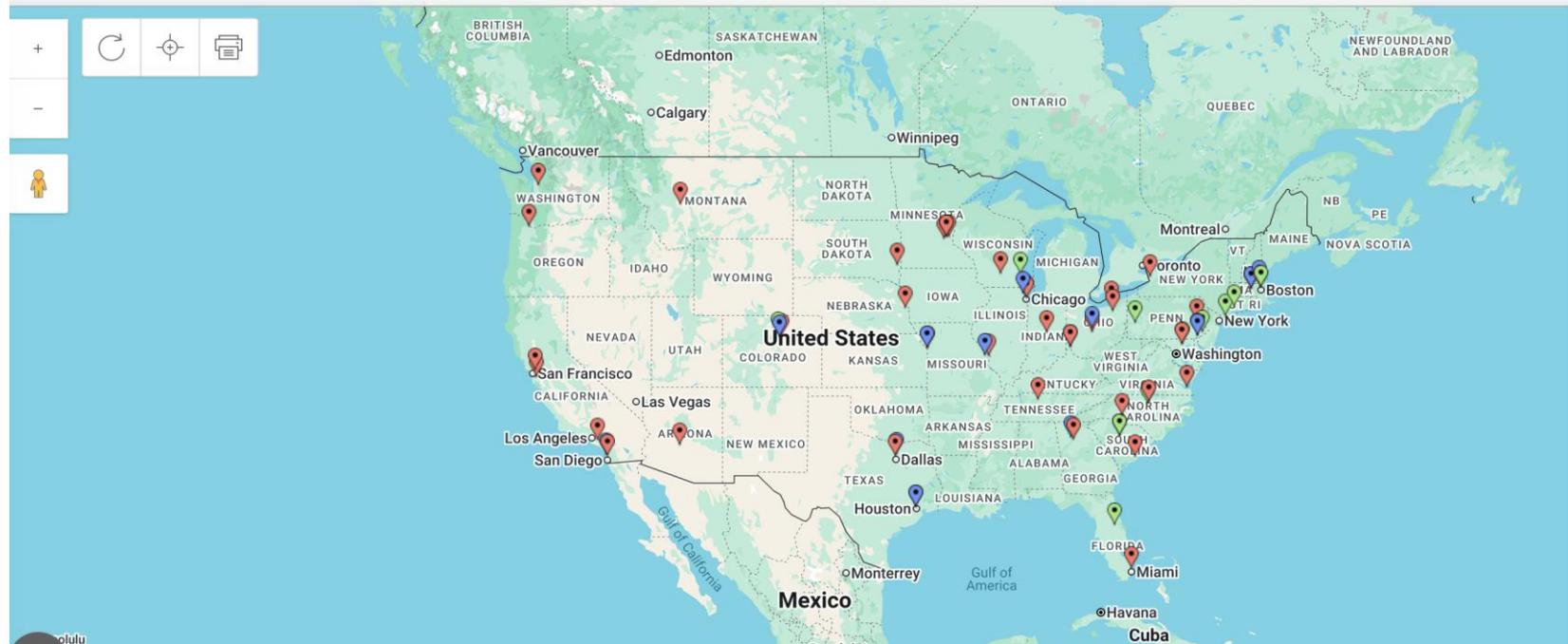
Only an estimated 5% of adults with Down syndrome in the U.S. have access to specialty Down syndrome clinics. That means 95% rely on you, their primary care professional.

About Us

Find a Clinician

National Down Syndrome Society - Clinic Map

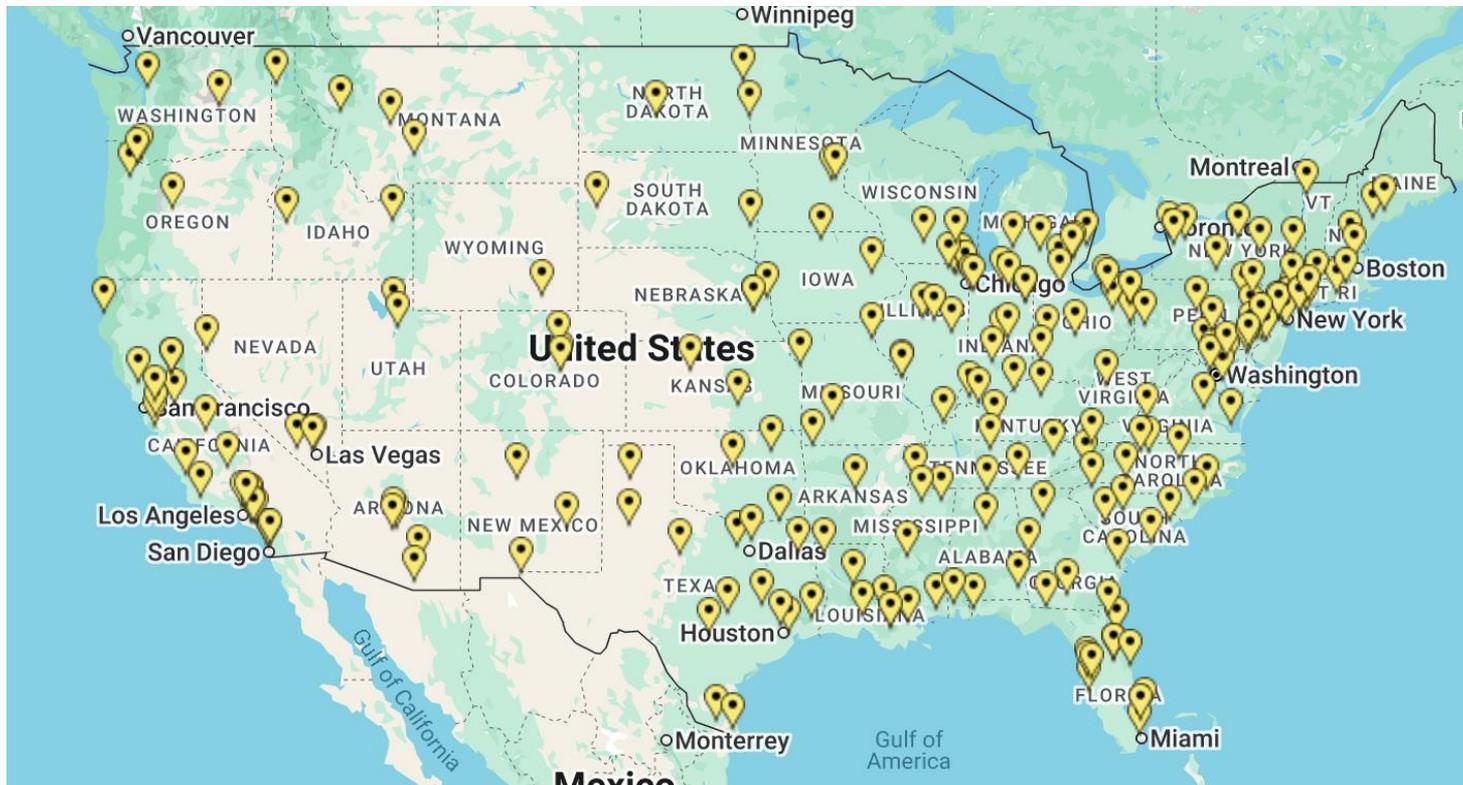
Search



[NDSS Find a Provider](#)

Connect with Families & Down Syndrome Organizations

<https://ndss.org/resources/local-support>



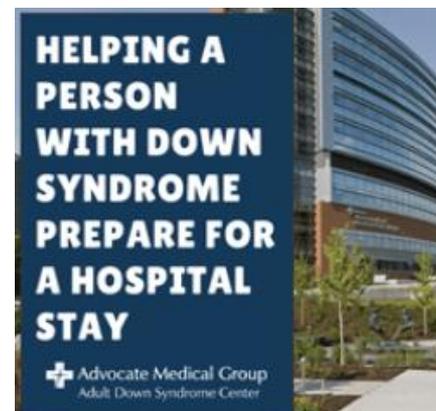
Desired Qualities of a Health Professional

- A belief that all individuals with Down syndrome deserve the same respect and care provided to any patient
- A willingness to listen to and learn from individuals with Down syndrome, families, care professionals, and other clinicians
- An understanding that problems that occur are not necessarily “just Down syndrome” (diagnostic overshadowing)

Prepare the Person with Down syndrome



[Medical Appointments](#)



[Hospital Stay](#)

Share Resources

- Understand that physicians and many other health professionals get limited training on caring for adults with Down syndrome
- A necessary opportunity to assist physicians and other health professionals improve their understanding of caring for adults with Down syndrome



[national down syndrome society](http://nationaldownsyndrome.org)

**A Clinical
Education and
Resource Hub for
Healthcare
Professionals**

caresds.org

**Elevating
Primary Care
for Adults with
Down
Syndrome**



national down syndrome society
ndss.

What You'll Find...



Self-Paced eLearning Course

- 2-hour eLearning course
- Covers topics such as common health conditions, avoiding diagnostic overshadowing, Down Syndrome Regression Disorder, and pain
- CME accredited for 2 credits
- No cost



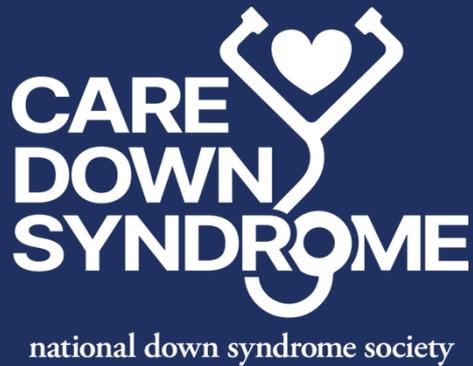
Reference Articles

- 17 Articles
- Peer-reviewed
- Each written on a different health related topic
- Topics include Alzheimer's disease, mental health, weight management, and sleep
- CME accredited for 0.25 credits each
- No cost



Resource Library

- Includes a list of external articles, websites, visuals, guidebooks, and more for medical professionals to use
- Downloadable patient education materials



Join us in elevating
primary care for **adults**
with **Down syndrome**



Visit **careds.org**
to learn more

Medical Care Guidelines

- Health Supervision for Children and Adolescents with Down Syndrome

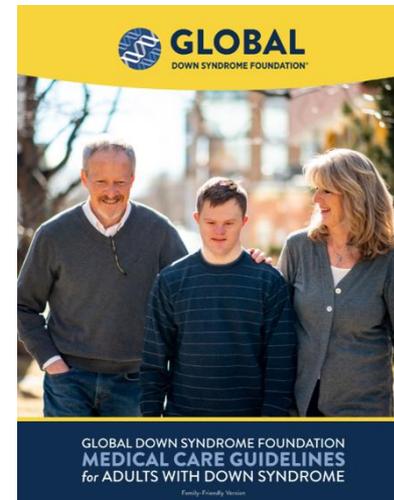
- GLOBAL Medical Care Guidelines for Adults with Down Syndrome

FROM THE AMERICAN ACADEMY OF PEDIATRICS

Supplemental Information

SUPPLEMENTAL FIGURE 1. Summary of Down syndrome-specific care.

Topic	1 yr	1 yr old to 1 yr	1 yr old to 5 yr	5 yr old to 12 yr	12 yr old to 21 yr
1. Confirm DS diagnosis with either CVS or amniocentesis prenatally or karyotype postnatally.	Yes	Yes	Yes	Yes	Yes
2. Review recurrence risk and offer the family referral to a clinical geneticist or genetic counselor.	Yes	Yes	Yes	Yes	Yes
3. Offer genetic counseling and support group information to the family.	Yes	Yes	Yes	Yes	Yes
4. Use CDC DS-specific growth charts to monitor weight, length, weight-for-length, head circumference, or BMI (use standard charts for BMI after age 12 years).	All healthcare visits				
5. Offer an echocardiogram to be read by a pediatric cardiologist.	Any visit				
6. Feeding assessment or video study if any: marked hypotonia, underweight child, low weight-for-length or BMI, slow feeding or choking with feeds, recurrent or persistent abnormal respiratory (coughing, wheezing) with feeds.	Any visit				
7. Consider objective hearing assessment (may be in HBM protocols) and follow DSD guidelines.	Up to 6 mo				
8. If the child is evaluated, refer to otolaryngologist for review with microphone until stable. TD and syndromically exact are possible.	Every 2-3 mo				
9. Consider early evaluation for hearing loss.	By age 3				
10. CBC with differential.	By age 3				
11. If TBM, make ongoing aware of management of leukemias (e.g., easy bruising/bleeding, recurrent fevers, bone pain).	All birth of child/1000	Every 5-7 mo	Annually, and every 6 mo if antibody antibodies ever detected		
12. Titer.	Annually		Through 2 yr		
13. RSV prophylaxis based on AAP guidelines.	Annually		Through 2 yr		
14. Discuss cervical spine positioning for procedures and atlantoaxial instability precautions.	All HBM		Biennially		
15. Assess for CMT and, discourage any smooth CMT practices.	All HBM		Up to 3 yr		
16. Refer children to early intervention for speech, fine motor or gross motor therapy.	Any visit				
17. If feasible, use disease-naïve, obtain developmentally appropriate hearing evaluation.	When ear chaf		After treatment		
18. Recurrent hearing with developmentally appropriate methodology (BNAER, behavioral, age-specific).	Based on DSM, every 6 mo until established normal hearing by ear-specific testing, then annually				
19. Refer to ophthalmologist with experience and expertise in children with disabilities.	By age 3				
20. CBC with differential if easy bruising or bleeding, recurrent fevers, or bone pain.	Any visit				
21. Assess for sleep-disordered breathing; if present, refer to physician.	At least once by 6 mo, then all subsequent HBM thereafter				

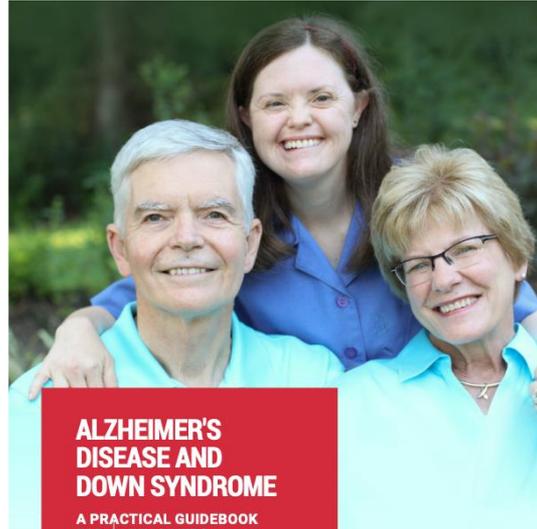


NDSS Guides



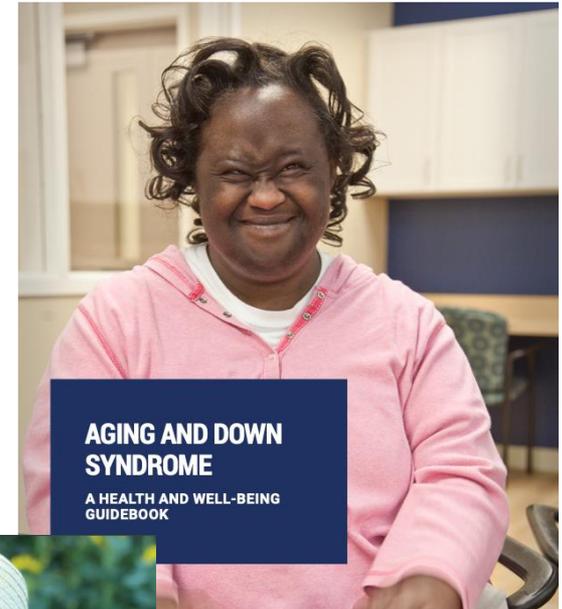
PRACTICING INCLUSIVE MENTAL HEALTHCARE

of Individuals with Down Syndrome



ALZHEIMER'S DISEASE AND DOWN SYNDROME

A PRACTICAL GUIDEBOOK FOR CAREGIVERS



AGING AND DOWN SYNDROME

A HEALTH AND WELL-BEING GUIDEBOOK

 national down syndrome society



END-OF-LIFE AND DOWN SYNDROME

A Companion Guidebook to
AGING AND DOWN SYNDROME:
A HEALTH AND WELL-BEING GUIDEBOOK

ALZHEIMER'S ASSOCIATION

 national down syndrome society

ALZHEIMER'S ASSOCIATION

 national down syndrome society

 national Task Group on Intellectual Disabilities and Development Practices

- [NDSS Healthcare Professional Resources](#)

 ALZHEIMER'S ASSOCIATION

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 Advocate Health Care

 AADM

 national down syndrome society

 Kramer Davis SMIG-USA

 national down syndrome society

Down Syndrome Medical Interest Group-USA

- Membership
- Webinars
- Annual symposium

Project ECHO

- Monthly virtual meeting for healthcare professionals
 - Attendees: panel of experts and clinicians seeking to learn more about Down syndrome
 - Opportunity to receive input on the care of a person with Down syndrome



DSMIG-USA
Down Syndrome Medical Interest Group

FREE RESOURCES

SHARE WITH YOUR HEALTH CARE PROVIDER

- Down Syndrome Project ECHO is a monthly virtual meeting for health care providers to learn and seek input from expert providers.
- The DSMIG Speaker Series consists of webinars and enduring materials designed to share knowledge and experience related to the care of people with Down syndrome and clinical research related to Down syndrome.
- DSMIG vetted resources including articles and important guidelines related to child and adult health issues, and health utilization by people with Down syndrome.

find out more at:
DSMIG-USA.ORG

The graphic features a blue background with a green and orange megaphone on the right side. A green banner with the text 'FREE RESOURCES' is positioned on the left. The DSMIG-USA logo is at the top right, and the website URL is at the bottom.

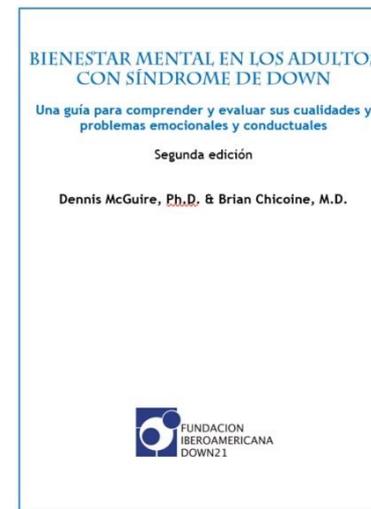
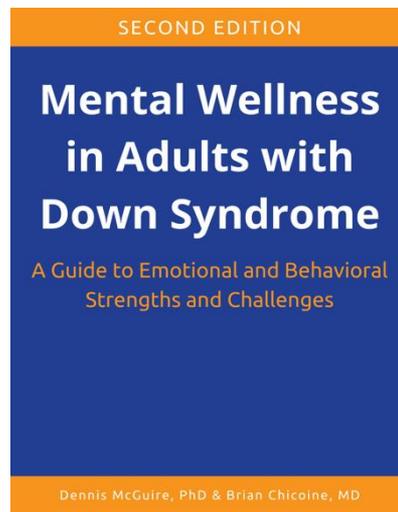
Resources for Health Promotion for Adults with Down Syndrome

- [Adult Down Syndrome Center Resource Library](#)
- [CARE Down Syndrome Resources](#)
- [Special Olympics Inclusive Health](#)

The screenshot shows the website for the Advocate Medical Group Adult Down Syndrome Center. The header includes the organization's name and a search bar. Below the header is a 'Resource Library | All Resources' section with three main categories: 'People with Down Syndrome', 'Families & Caregivers', and 'Health Care Professionals'. Each category has a representative image and a person icon. Below these categories is a navigation menu with five items: 'Events, Classes & Programs' (with a bell icon), 'Video Gallery' (with a play button icon), 'Related Organizations' (with a magnifying glass icon), 'Projects' (with a book icon), and 'News' (with a document icon). Each menu item has a 'See the Schedule' or 'View All' link. Below the navigation menu is the Special Olympics logo and a banner for 'Inclusive Health' featuring a group of diverse people. The banner text reads: 'Despite severe need and higher health risks, people with intellectual disabilities (ID) are often denied health services and die on average 16 years sooner than the general population.' Below the banner is a paragraph of text: 'Special Olympics Health, made possible by the Golisano Foundation, and in the United States in collaboration with the U.S. Centers for Disease Control and Prevention, is creating a world where people with intellectual disabilities have every opportunity to be healthy.' There is an 'Accessibility' button in the bottom right corner of the banner area.

Additional Resources

Mental Wellness in Adults with Down Syndrome



Available as a free PDF in English and Spanish

Additional Resources

- [Down Syndrome Clinic to You \(DSC2U\)](#)
- [NTG Family Caregiver Resources](#)

Questions?

- Please use “Q and A” function

Thank you!

Head to www.ndss.org for more information and additional resources.